Identification of Children with Developmental Disabilities Through a Team-Based Approach

Capstone

Presented in Partial Fulfillment of the Requirements for the Degree Doctorate of Audiology in the Graduate School of The Ohio State University

By

Courtney Lori Abel, B.A.

Graduate Program in Audiology

The Ohio State University

2011

Capstone Committee:

Christina Roup, Advisor

Gail Whitelaw

Julie Hazelbaker

Abstract

Over the past 50 years, legislative initiatives within the United States have improved access to early intervention services for children with developmental disabilities and their families. The goal of early intervention is to minimize the impact of the child's disability, and provide the appropriate community supports to allow each individual to reach their maximum developmental potential. The current early intervention model advocates for a team based approach to the assessment and management of developmental disabilities, with parents as active members of the team. Multidisciplinary and interdisciplinary teams are an effective way to deliver services to the child and their family. It is beneficial for each professional to be familiar with child development and the expertise of other team members in order to identify potential risk factors in their patients, which can lead to appropriate and timely referrals to other health care providers.

Dedication

Dedicated to the students at The Ohio State University

Vita

June 2003.....Sycamore High School

June 2007.....B.A. Social and Behavioral Science, The Ohio State University

Fields of Study

Major Field: Audiology

Table of Contents

List of Tables

Chapter 1: Purpose of the Literature Review

This literature review is focused on the current model of identification and assessment of children with developmental disabilities from the perspective of multiple disciplines. It should provide a framework for understanding the contributions and expertise offered from a selection of disciplines who are often involved in the provision of care for this population. Developmental milestones are explored to illustrate the hierarchical and predictable structures of normal child development, and to highlight the complex interaction of all developmental domains. Basic assessment methods utilized by each of the disciplines are discussed in order to provide perspective in regards to the discipline-specific contributions that are made by each of the team members. Due to the heterogeneity and dynamic needs of individuals with developmental disabilities, discussion of specific treatment options are beyond the scope of this review. Finally, this paper discusses the benefits and limitations of a multidisciplinary and interdisciplinary team approach to identification of children with developmental disabilities.

Chapter 2: Introduction to the Historical Context of Developmental Disability Policy

In years past, individuals with developmental disabilities were withheld from fully participating in community activities due to a prevailing attitude that they did not belong in society. People with disabilities were often institutionalized and denied access to education. Today, people with disabilities are very much a part of our communities as a result of a progressive movement aimed at inclusion and providing these individuals with the same rights exercised by every other citizen in the United States (Brown & Radford, 2007). The prevalence of individuals with a developmental disability or [intellectual disability] in the United States has been estimated to be 14.9 per 1,000 people (Larson et al., 2001). A wide range of etiologies are known to cause developmental disability, including but not limited to: genetic abnormalities, environmental factors, birth complications, infections, and a combination of any of these factors (Rice et al., 2004). The exact etiology cannot be identified in approximately 80% of patients, further complicating the diagnostic and treatment planning process for these individuals. Out of the known etiologies of intellectual disability, Down syndrome, is the most commonly identified genetic anomaly (Rauch et al., 2006).

The identification, treatment, and management of individuals with developmental disabilities has evolved significantly in recent history as a result of key legislative initiatives aimed at improving the quality of life for a population that has historically

been disregarded by society. In 1963, President John F. Kennedy signed public law (PL 88-164) which commissioned the creation of University Affiliated Facilities (UAF) (Fifield & Fifield, 1995). These facilities are known today as The Association of University Centers on Disabilities (AUCD), which encompasses both the University Centers for Excellence in Developmental Disabilities (UCEDD) and the Leadership Education in Neurodevelopmental Disabilities (LEND) programs. The LEND program is a clinically based training initiative that is funded through the United States Bureau of Maternal and Childhood Health (BMCH). A fundamental goal of the program is to prepare professionals on coordinated assessment and management of children with developmental and related disabilities using an interdisciplinary team approach (AUCD, 2010) for the purpose of improving both short and long-term outcomes of the children and communities served. There is a significant amount of empirical evidence which has emerged over the last fifty years to support early identification and intervention of individuals who have, or who are at risk for, a developmental disability (Guralnick, 2011).

Definitions of developmental and intellectual disability vary widely within the literature and across vested organizations, in part due to the heterogeneous presentation of the population itself. Individuals with developmental disabilities present with varying etiologies, physical anomalies, cognitive impairments, and physical impairments. There are a profusion of groups, organizations, and governmental agencies that have established their own set of definitions and criteria to classify individuals with developmental disabilities. This section of the review is intended to clarify some of the terminology and

classification schemes that are commonly used in discussing individuals with developmental disabilities.

The American Association on Intellectual and Developmental Disability (AAIDD) defines this population as having a "disability [presenting prior to the age of 18,] characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" (AAIDD, 2010). These limitations can manifest in delayed speech and language skills, impaired social or communication skills, impaired fine and gross motor skills (Shapiro, Menon, & Accardo, 2008), or a combination of any of these factors (Shevell, 2010).

The term *developmental delay* is often used to describe young children who are delayed in achieving developmental milestones, although it is sometimes used synonymously with *mental retardation* (Moeschler et al., 2006; Peterson, Kube, & Palmer, 1998). Generally speaking, developmental delay is a provisional term used until a more definitive diagnosis can be assigned based on norm-referenced assessment tools. It is often difficult for healthcare providers to obtain accurate norm-referenced assessments on infants and toddlers who present with developmental concerns, making a diagnosis of intellectual disability elusive until the child is older (Petersen, Kube, & Palmer, 1998). In recent years, there has been a movement within the developmental disability community to replace the term "mental retardation" with *intellectual disability*. And so, while the terms are sometimes used interchangeably, intellectual disability is considered to be the modern and more appropriate terminology.

The National Center for Medical Rehabilitation Research (NC-MRR) developed a model which demonstrates the complexity of defining disabilities through a set of five

domains as a function of their impact. Table 1 illustrates the hierarchical structure of these domains: etiology, pathophysiology, impairment, functional limitation, disability, and societal limitations. The purpose of the NC-MRR classification model was to, "ensure that clinical rehabilitation research addressed the full range of outcome domains for people with disabilities" (Petersen, Kube, & Palmer, 1998, pg. 3).

It is important for professionals working with children with disabilities to understand the variability that exists with respect to terminology and classification schemes utilized by different organizations and agencies. This can ultimately minimize misunderstandings and lead to better patient care and coordination of resources.

Table 1. Domains in Disability Classification

Domains	Definition	Level of Impacts
Etiology	Causal factor or cause of a disease or disorder	Molecular, cell, tissue, organ, or system of organs
Pathophysiology	Interruption of, or interference with, normal physiological and developmental process or structures. The pathophysiologic level focuses on cellular, structural, or functional events subsequent to injury, disease, or genetic abnormality.	Cell and tissues
Impairment	Loss or abnormality of cognitive, emotional, physiological, or anatomical structure or function. Including all losses or abnormalities, not just those attributable to the initial pathophysiology.	Organs and systems of organs
Functional limitation	Restriction, or lack of ability to perform an action in the manner or within a range consistent with the purpose of an organ or organ system.	Function of organ and organ system
Disability	Inability or limitation in performing tasks, activities, and roles to levels expected within physical and social contexts.	Individual
Societal limitations	Restriction, attributable to social policy or barriers (structural or attitudinal), which limits fulfillment of roles or denies access to services and opportunities that are associated with full participation in society	Society

Note. From NIH publication 93-3509. As cited in M. Petersen & D. Kube (1998) Palmer, F. *Classification of Developmental Delays*. p. 3

Early Intervention

It would be imprudent to discuss identification of individuals with developmental disabilities without first discussing early intervention and the impact that it has had in improving the outcomes of children who are at risk for a developmental disability. Early intervention refers to a variety of child and family oriented services and supports, which are aimed at addressing the needs and goals of the child and their family members (Bell et al., 2010). The current model is the yield of many years of legislative efforts that sought to define eligibility criteria and expand the rights and services available to individuals with developmental disabilities and their families. In practice, early intervention not only seeks to serve children who are at biological risk, but also children who are susceptible to environmental risks (Guralnick, 2011). Current models of early intervention support a family-centered approach, where the parents and family members of the individual are regarded as active members of the team. Additionally, interventions are coordinated, evidence-based, and individualized based on the needs of the patient and their families (Guralnick, 2011).

In the United States, early intervention is outlined in Part C of the Individuals with Disabilities Education Act (IDEA) of 2004. This portion of the IDEA act targets children from birth to three years of age. Eligibility criteria differs in each state, as each state is left to independently interpret the act. This makes it difficult to examine the efficacy and eligibility of Part C of the IDEA act, as early intervention services are carried out differently from state to state. It was estimated that approximately 265,000

children received some type of service under Part C of the IDEA act in 2002, although it is likely that many more children are eligible. In fact, only 10% of children who were likely to be eligible for services were actually enrolled (Rosenberg, Zang, & Robinson, 2008). This demonstrates the need for professionals who work with children with disabilities to help the families connect to resources within their community, as well as help parents navigate this complex system.

Chapter 3: The Team Approach to Identification and Assessment of Individuals with Developmental Disabilities

Current early intervention programs support the use of a coordinated team approach to medical care for children with disabilities as a means to improve the quality of care, increase efficiency in diagnosis and management of the patient, and increase satisfaction of the parents and caregivers, among other benefits (Patel, Pratt, & Patel, 2008). A functional team requires collaboration, effective communication strategies, and a reliance on the expertise of other members. It also requires that each member of the team fulfill the duties and expectations of their role. Functional teams seek to engage in self-reflection to identify areas of strength and weakness. The ultimate goal of the team approach is to identify and address the needs of the patient and their family members, with the understanding that the family members are responsible for the final decision making (Frankel & Gold, 2007). The number of individuals on the team inherently varies according to the needs of the child and their family members, but can include as many as 10 members (Patel et al., 2008). As the needs of the patient evolve over time, the members of the team also change (Frankel & Gold, 2007). The team may include a speech-language pathologist, pediatrician. audiologist, occupational therapist, physical

therapist, social worker, nurse, medical dietician, dentist, and many other health care providers (Patel, Pratt, & Patel, 2008).

Professionals providing services to children with disabilities can do so independently or as part of a team. It is important to distinguish the different team approaches often utilized in the health care field: multidisciplinary and interdisciplinary. Within the *multidisciplinary* team approach, each professional individually meets with the child and family. They evaluate the child within the confines of their own discipline. Each professional creates and implements their own treatment plans, without direct input from other members of the team. This approach limits the amount of collaboration and shared responsibility between team members. Additionally, physicians or pediatricians often serve as the "leader" of the group (Patel, Pratt, & Patel, 2008).

An *interdisciplinary* approach is characterized by a shared responsibility of all team members in the identification, assessment, and procurement of services for the child and their families. It also implies equal partnerships with a shared responsibility amongst team members when it comes to making decisions and problem solving. In this approach, the professionals interact with each other on a more integrated level, while drawing on their knowledge of other disciplines when assessing and making treatment recommendations. The entire team assumes a shared responsibility in generating and implementing the treatment plan (Patel, Pratt, & Patel, 2008). Table 2 provides a more detailed outline of the defining characteristics of multidisciplinary and interdisciplinary teams. There are a number of benefits to a team-based approach in serving children with developmental disabilities, including a reduction in repetitive assessments and services, increased quality of care, and higher satisfaction among families (Patel, Pratt, & Patel,

2008).

Table 2. Comparison of Multidisciplinary and Interdisciplinary Approaches

Multidisciplinary	**Interdisciplinary**
Working with several disciplines	Working between several disciplines
Involves more than two disciplines	Involves two disciplines (ie, focuses on reciprocal action of disciplines)
Members from different disciplines working independently on different aspects of a project, working in parallel or sequentially	Members from different disciplines working together on the same project, working jointly
Individual goals in different professions	Shared goals
Participants have separate but interrelated roles	Participants have common roles
Participants maintain own disciplinary roles	Participants surrender some aspects of their own disciplinary role but still maintain a discipline-specific base
Does not challenge disciplinary boundaries	Blurring of disciplinary boundaries
Summation and juxtaposition of disciplines	Integration and synthesis of disciplines
Additive, integrative, collaborative	Interactive, integrative, collaborative
Graphically analogous to two totally separate circles	Graphically analogous to two partially overlapping circles
External coherence (ie, motivated by a desire to focus on clients' needs)	Internal coherence (ie, motivated by a desire to focus on the team needs)
Participants learn about each other	Participants learn about and from each other
Separate methodologies	Common methodologies
Instrumental, use of complementary knowledge or perspectives to address a question	Epistemological, creation of new knowledge or perspective, even new disciplines
Outcome is the sum of the individual parts	Outcome is more than the sum of the individual parts
Graphically analogous to a horizontal series of compartments, each linked by a vertical unidirectional arrow to a higher "control" compartment above	Graphically analogous to a horizontal series of compartments, each linked by a vertical unidirectional arrow to a higher "control" compartment above, also with horizontal bidirectional arrows between pairs of horizontal compartments

Note. Adapted from "Multidisciplinarity, interdisciplinarity and transdisciplinarity in health research, services, education and policy: 1. Definitions, objectives, and evidence of effectiveness". By BC Choi & AW Pak, 2006, *Clin Invest Med,* 29:356.

Chapter 4: The Role of the Primary Care Physician and Pediatrician in the Screening and Assessment of Children with Developmental Disabilities

Introduction to the Physician's Role

Primary care physicians and pediatricians play a critical role in the diagnosis and treatment of children with developmental disabilities, as they often serve as the first point of contact for parents and caregivers to express their concerns (AAP, 2006). Preventive care visits within the first five years of life serve as an opportunity for the physician to perform developmental surveillance and implement standardized screening tools when indicated (AAP, 2006). Physicians are often responsible for delivering information to the parents regarding the etiology of the disability, communicating results from diagnostic testing, making referrals to other health care professionals for additional evaluations and intervention therapies (Moeschler & Shevell, 2006), and integrating recommendations offered by other professionals in the the treatment planning process (AAP, 2006).

Once a child is identified as having a developmental delay, a significant amount of effort is exerted in identifying the etiology of the disorder through a battery of diagnostic and laboratory investigations (Shevell et al., 2003). Identification of the etiology "has specific implications regarding treatment, prognosis, ongoing medical management of associated conditions, assessment of recurrence risk, counseling of families if there is a risk of recurrence,...implementation of prevention programs,

[and]...limits further unnecessary testing" (Shevell et al., 2003, pg. 368). The "medical home model" for coordinated care places responsibility on the physician, family, subspecialty health care providers, and the community to implement a dynamic treatment plan which addresses the specific and evolving needs of the child and their family members (AAP, 2006).

The medical evaluation of a child identified as having a developmental delay is extensive and may consist of a series of formal and informal developmental assessments, genetics evaluations, imaging studies, and laboratory studies. The purpose of the investigation involves: "(1) confirming and classifying the precise neurodevelopmental disability; (2) through history, physical examination, and selective laboratory testing, ascertaining a possible underlying etiology; (3) identifying and arranging for needed supports and rehabilitation service interventions; (4) counseling the family regarding the implications of the diagnosis from individual and familial perspectives, including a discussion of possible recurrence risks and possible outcomes; and (5) identifying possible intercurrent medical or behavioral conditions that may require specific medical or other interventions to optimize the realization of the child's full developmental and cognitive potential" (Shevell, 2008, pg. 1073).

Case History

Procuring a detailed case history is an essential element of the medical evaluation, as it can render clues regarding the etiology or onset of the disability and can provide a more transparent direction for further exploration. A three generation familial history of the child should be researched, with a directed interest in family members' developmental and health conditions. The mother's pregnancy history, including the use

of medications and harmful substances, potentially detrimental events that occurred throughout the pregnancy and delivery process, and the mode of delivery is important information for the physician to obtain. Additional avenues to be explored include objective parameters such as, "the child's birth weight, activity, pulse, grimace, appearance, respiration (APGAR) scores...the duration of an infant's postnatal stay; and the occurrence of any relevant neurologic symptoms as a newborn" (Shevell, 2008, pg. 1074). An examination of the child's complete medical history is essential, including any illnesses and use of medications, in addition to evaluations from other health care professionals (Shevell, 2006; Shevell, 2008). Demographic information about the family and caregivers is relevant information that should be ascertained, including the marital status of the parents or caregivers, their socioeconomic status, and highest education level obtained. This information can point to additional risk factors that should be explored or monitored (Shevell, 2006; Shevell, 2008), and may also indicate the need for referral to additional resources available within the community.

Developmental History and Milestones

A comprehensive developmental history is the cornerstone of the clinical evaluation. This information can be obtained through informal and formal measures and observations. The AAP promotes the concept of "developmental surveillance", where the physician assumes the role of probing and recording the child's developmental status through addressing parental concerns, directly observing the child, and recognizing factors that could put the child at risk for a developmental disability over a period of time. Hence, developmental surveillance is not a principle that is carried out in the course of a single office visit, but is a dynamic process that occurs over a period of time

and throughout multiple interactions and visits with the child (AAP, 2006). Table 3 outlines developmental milestones from 2 months to 24 months of age. It highlights major milestones in speech and language development and motor development. This table can be utilized by health care professionals to gage the overall development of a child.

Table 3. Guide to Early Child Development and Functional Milestones

	Motor	Language	Social/play
2 months	Head up in prone		Smiles, fixes, and follows
3 months	Head/chest up in prone, grasp placed object	Coos	Laughs
4 months	Rolls, reaches		
6 months	Sits with supports, transfers	Babbles, turns to sound	Mouthing objects
8 months	Sits without support, weight bears	Turns to name	
10 months	Pincer grasp, starting to cruise, crawling	"Bye-bye" wave	Drinks from cup
12 months	Walks but falls easily	First words	Finger feeds, objects in and out of containers
15 months	Walks steadily, scribbling	Pointing, multiple single words	Spoon use, assists in dressing
18 months	Up/down stairs with assistance, climbing, throws ball	Two-word phrases, pointing to body parts	Build towers, play with others
24 months	Up/down stairs, 1 step @ time, kicks ball	Three-word phrases, pronoun	

Data from M. Shevell. 2006. Office evaluation of the child with developmental delay. *Seminars in Pediatric Neurology.* p. 256-261.

Physical Examination

There are a number of developmental disabilities and syndromes that present with identifying physical anomalies or dysmorphic features, making a thorough physical examination of the child another important aspect of a comprehensive medical examination. Results from the physical examination "may (1) confirm an etiologic suspicion suggested originally by history, (2) put forward a novel etiologic possibility previously unsuspected, (3) document findings that may suggest a heightened probability of finding an etiology on screening tests" (Shevell, 2006, pg. 258). Objective information including height, weight, and head circumference are measured and the corresponding percentile rank is assessed. This information must also be interpreted with respect to the child's ethnicity and inherited physical features. For example, it may be necessary to measure and plot the parents and siblings head circumferences as well, in order to determine whether the child's head circumference is truly an aberration or the result of an inherited trait. Also in the physical examination, the physician looks for "possible stigmata of a neurocutaneuous disorder (ie, café-au-lait spots and hypomelanotic macules) or myelodysplasia...[and] hepatosplenomegaly and coarsening of the facies [that may indicate] an underlying storage disorder" (Shevell, 2006, pg. 258).

A neurologic assessment is another element of the physical examination which includes clinical evaluation of the integrity of the cranial nerves "to document any possible aberrant pupillary responses, visual field defects, retinal abnormalities, nystagmus, facial paresis, excessive drooling, head tilt, dysphagia, or dysarthria"

(Shevell, 2006, pg. 258). The physician observes the child's motor functions for any "lateralizing features, asymmetries, or dyskinesias (i.e., dystonia, athetosis, chorea, and tremor)" (Shevell, 2006, pg. 258).

There is not a standard test battery that fits the needs of every single patient who presents with a developmental delay. The physician selects additional diagnostic laboratory and imaging studies based on the information obtained in the case history, developmental history, and physical examination of the child.

Metabolic Testing

The physician may order metabolic studies in cases where an inborn error of metabolism is suspected, and sometimes as a routine component of the investigation. Inborn errors of metabolism are rare single-gene disorders that "occur when cells cannot produce proteins or enzymes needed to convert certain chemicals into others or when cells cannot transport substances from one place to another" (Percy, Lewkis, & Brown, 2007, pg. 96). There are hundreds of known inborn errors of metabolism that typically result in detrimental effects to the nervous system if not managed properly (Percy, Lewkis, & Brown, 2007). Infants in the United States are screened at birth for this type of disorder through spectrometry, amino and organic acids, capillary blood gas, and thyroid and liver function tests (Shevell et al., 2003; Shevell, 2006; Shevell, 2008). Early detection of this variety of chromosomal abnormalities has resulted in a decrease in the number of preventable neurodevelopmental disabilities. These children may present with "failure to thrive, developmental regression, episodic decompensation...hepatosplenomegaly, [or] coarse facial features" (Shevell et al., 2003, pg. 369). Table 4 provides a more comprehensive outline of risk factors that may

indicate the presence of a metabolic disorder.

Table 4. Selected Clinical Findings or Laboratory Abnormalities Suggesting a Metabolic Disorder

Failure of appropriate growth
Recurrent unexplained illness
Seizures
Ataxia
Loss of psychomotor skills
Hypotonia
"Coarse" appearance
Eye abnormalities (cataracts, opthalmoplegia, corneal clouding, abnormal retina)
Recurrent somnolence/coma
Abnormal sexual differentiation
Arachnodactyly
Hepatosplenomegaly
Metabolic/lactic acidosis
Hyperuricemia
Hyperammonemia
Low cholesterol
Structural hair abnormalities
Unexplained deafness
Bone abnormalities (dyostosis, occipital horns, punctuate calcifications)
Skin abnormalities (angiokeratoma, "orange-peel" skin, ichthyosis)

Note: From J. Moeschler, M. Shevell,, and the Committee on Genetics. (2006). Clinical genetic evaluation of the child with mental retardation or developmental delays. Data from Curry, CJ., Stevenson, RE., Aughton, D., et al. Evaluation of mental retardation: recommendations of a consensus conference--American College of Medical Genetics. *Am J Med Genet,* 1997; 72:468-477.

Research on the yield of metabolic testing as a routine investigation for children with developmental disability is estimated at 1%. In cases when pertinent risk factors are identified by the physician through the history and physical examination, the yield improves to approximately 5%. Thus, identifying a metabolic disorder through this type of testing is more successful when there is corroborating evidence in the child's history and physical examination (Shevell et al., 2003).

Cytogenetic Analysis

Cytogenetic analysis is indicated in all cases of idiopathic developmental or intellectual disability. A routine chromosomal analysis using G-banding (400-550 bands per haploid karyotype) "permit the identification of the alternating light and dark staining bands comprising each chromosome, the detection of aneuploidy (extra or missing chromosomes), and the identification of microscopically apparent structural aberrations, including deletions and translocations" (Shaffer, 2005, pg. 651). This type of laboratory investigation most commonly identifies, "Down syndrome, sex chromosome aneuploidies (47, XXY), fragile X syndrome, and unbalanced translocation/deletion syndromes" (Shevell et al., 2003, pg. 370). Research on the yield of chromosomal analysis for children with developmental disability is estimated at 3.7%, with studies ranging from 2.93% to 11.6%. The variation in the range is likely attributed to the type of cytogenetic testing used in the study, as well as the resolution selected (Shevell et al., 2003).

High-resolution chromosomal analysis (≥550 bands) "involves the synchronization of lymphocyte cultures to achieve a population of cells in prophase and prometaphase" (Shaffer, 2005, pg. 651) and is indicated for the purpose of "[detecting]

microdeletions, microduplications, or subtle translocations" (Shaffer, 2005, pg. 651). This technique allows the differentiation of up to 1000 bands, thus improving the possibility of identifying smaller structural abnormalities (Shaffer, 2005).

Molecular Cytogenetic Analysis

Fluorescence in situ hybridization (FISH) testing is indicated when a child presents with a phenotype that is consistent with a specific chromosomal microdeletion or microduplication that cannot be identified through routine or high-resolution chromosomal analysis (Shaffer, 2005). Research on the yield of FISH testing for individuals with a moderate or severe developmental delay is estimated at 6.8%. The parents of the child may also undergo FISH testing to determine whether they carry the same abnormality (Shevell et al., 2003).

Fragile X Testing

Laboratory testing for Fragile X syndrome is indicated in idiopathic cases of intellectual disability in males. Fragile X syndrome is an inherited single gene disorder which occurs when there is a mutation to the FMR1 gene on the X chromosome. It occurs more frequently in males than females, with males presenting with a more severe phenotype. Clinical manifestations may include intellectual and developmental disability with varying degrees of severity, autistic-like behaviors, large pinna, and a long, narrow face (Mazzocco & Holden, 2007). The diagnostic yield using current molecular screening of the FMR1 gene is approximately 2.6%. The yield increased to 7.6% when the individuals presented with one or more of the clinical manifestations including "family history of mental retardation, facial features including either a long jaw or high forehead, large and/or protuberant ears, hyperextendible joints, soft and velvety palmar

skin with redundancy on the dorsum of the hand, enlargement of the testes, and personality attributes with initial shyness and lack of eye contact followed by friendliness and verbosity" (Shevell et al., 2003, pg. 371).

Rett Syndrome Testing

Testing for Rett syndrome is indicated in cases of idiopathic intellectual disability in females (Shevell et al., 2003). Rett syndrome is a neurodevelopmental disability which affects females, and most often occurs as a result of a mutation or deletion of the X-linked MeCP2 gene (Berger-Sweeney, 2011; Shevell et al., 2003). Clinical manifestations include seemingly normal development until anywhere from 6 to 18 months of age, marked by a subsequent regression in skills that were initially obtained at the expected rate. This includes a regression in speech, language, and motor skills. Other clinical signs often seen in females with Rett syndrome include, "seizures, autistic-like behavior, ataxia, intermittent hyperventilation, and stereotypic hand movements" (Shevell et al., 2003, pg. 371). It is considered to be a leading cause of intellectual disability in females (Berger-Sweeney, 2011).

Imaging Studies

Neuroimaging studies such as the computed tomography (CT) scan and magnetic resonance imaging (MRI) may be ordered by a physician to determine etiology, particularly when a disorder of the central nervous system is suspected. CT scans performed on a screening basis have a yield of 30% of children in detecting abnormalities. MRI studies have a diagnostic yield of approximately 48.6% to 65.5% in detecting abnormalities, making it the more preferable imaging tool in cases where the physician must decide between the two studies (Shevell et al., 2003). It should be noted

that an abnormality identified through an MRI results in an actual diagnosis, syndromic or otherwise, in only as many as 3.9% of cases (Moeschler, 2008). MRI investigations in a recent study of 80 children who presented with a sensorineural hearing loss revealed normal results in 55% of the patients (Chilosi et al., 2010). Of the abnormal MRI studies, white matter abnormalities were identified in 54% of the cases and brain malformations were identified in 38% of the cases. The study also indicated a statistically significant association between the brain abnormalities and disability (Chilosi et al., 2010).

Summary

Physicians play an integral role in the identification and treatment planning for individuals with developmental disabilities. They are charged with identifying any risk factors associated with developmental disabilities, ordering laboratory and imaging studies based on the most current evidence-based practices, and directing the child and their families to allied health care professionals and community resources. The physician often acts as the "medical home" for the child and their family, implicating a great deal of responsibility as a member of the multidisciplinary or interdisciplinary team.

Chapter 5: Hearing Loss and the Audiologists Role in the Identification of Children with Developmental Disability

Normal Development of the Auditory System

Human infants are born with adult-like inner ear structures, allowing for normal peripheral hearing acuity at birth. Peripheral tuning, or the ability of tonotopically organized neurons within the cochlea to fire to specific frequencies, is present at birth. However, tuning in the central auditory pathway, which requires neuronal maturation, is not developed until approximately six months of age (Sininger, Doyle, & Moore, 1999). Changes in the auditory brainstem response (ABR) over the first two years of life, particularly the morphology of the waveform and peak latencies of the response (Sininger, 2007), suggest that the brainstem does not reach maturity until approximately 2 to 3 years of life. This is around the same time that the cortical structures in the human auditory system reach some degree of maturity as a result of myelination of afferent and efferent pathways (Sininger, Doyle, & Moore, 1999).

Newborn infants demonstrate the ability to localize sound sources shortly after birth. Sound localization occurs as a result of the head-shadow effect, in which interaural temporal and interaural level differences of a stimulus are used to determine the angle of

the sound source. The behavioral localization response of an infant is relatively uncommon between 2-3 months of age, but increases again between 5-6 months of age (Ashmead et al., 1991; Sininger, Doyle, & Moore, 1999). This skill relies on the ability for the infant to perceive minute differences between ears at the very same time the size and shape of their head and pinna are growing and changing. This would suggest that infants are constantly integrating their auditory and visual experiences in order to master this skill (i.e. pairing the sound source with a visual "reward" when they are able to locate the stimulus). Accuracy in the child's ability to localize sound sources accelerate through the first year of life and achieves "adult-like" performance by approximately five years of age (Sininger, Doyle, & Moore, 1999).

Speech perception is a sophisticated, and perhaps the most important function of humanity. Infants require consistent exposure to sounds and language so that the central auditory pathway has the opportunity to mature. Infants show a proclivity for human speech over other sound sources in their environment shortly after birth (Krentz & Corina, 2008). They even demonstrate a preference for their mother's voice and vowel sounds over other environmental stimuli (Sininger, Doyle, & Moore, 1999). Between 6 and 8 months of age, infants are able to detect differences in consonant contrasts that are found in their primary language, as well as foreign languages. However, around 10 months of age their aptitude to discriminate consonants not encountered in their native language dissipates in favor of more familiar sounds (Krentz & Corina, 2008). This reinforces the idea that early sensory experiences have a significant impact on a child's auditory and speech and language development (Sininger, Doyle, & Moore, 1999).

Deprivation of consistent auditory stimulation can have detrimental effects on a developing child's auditory system. Both sensorineural and conductive hearing losses prevent the stimulation and experience necessary for the rapidly developing auditory system to mature normally, even in cases of unilateral loss (Sininger, Doyle, & Moore, 1999). One study found that even following surgical correction of a conductive hearing loss in patients, they continued to demonstrate smaller than expected masking level differences (Pillsbury et al., 1991). Hence, there is a critical period in the development of the auditory system which, if not properly stimulated, can lead to irreversible auditory deficits (Sininger, Doyle, & Moore, 1999).

Early Intervention for Children with Hearing Impairment

Research has consistently demonstrated that early diagnosis and treatment of hearing loss is essential in order for infants to achieve normal speech and language developmental milestones. The first 6 months of life is a particularly crucial time period for identifying hearing loss in a child (Yoshinaga-Itano et al., 1998), allowing time for intensive and appropriate intervention to take place prior to the critical period of language learning. With early intervention, a child identified with a hearing loss can have an outcome that matches the skills of children with normal hearing (Yoshinaga-Itano et al., 1998). Currently, all 50 states have guidelines for newborn hearing screening (UNHS) programs. Prior to the widespread implementation of screening programs, the average age of identification exceeded two years of age (Vohr et al., 2008).

Since the majority of children with congenital hearing loss are now being assessed and identified as infants, many of the clinical manifestations of a developmental disability are not readily apparent to the audiologist and other professionals working with

the child and their family. This is especially the case if the infant does not present with any obvious physical anomalies or a birth or family history which would otherwise indicate a higher risk for a developmental disability. The Joint Committee on Infant Hearing (JCIH) established a set of risk factors to help identify children who are at a higher risk for hearing loss:

I. Indicators for use with neonates (birth through 28 days) where universal hearing screening is not yet available:
   A. An illness or condition requiring admission of 48 hours or longer to a neonatal intensive care unit
   B. Stigmata or other findings associated with a syndrome known to include a sensorineural and or conductive hearing loss
   C. Family history of permanent childhood sensorineural hearing loss
   D. Craniofacial anomalies, including those with morphologic abnormalities of the pinna and ear canal
   E. In utero infection such as cytomegalovirus, herpes, toxoplasmosis, or rubella

II. Indicators for use with neonates or infants (29 days through 2 years); any infant with these risk indicators who has passed the birth screen should, nonetheless, receive audiologic monitoring every 6 months until age 3 years:
   A. Parental or caregiver concern regarding hearing, speech, language, and or developmental delay
   B. Family history of permanent childhood hearing loss
   C. Stigmata or other findings associated with a syndrome known to include a sensorineural or conductive hearing loss or eustachian tube dysfunction
   D. Postnatal infections associated with sensorineural hearing loss, including bacterial meningitis
   E. In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
   F. Neonatal indicators--specifically hyperbilirubinemia at a serum level requiring exchange transfusion, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, and conditions requiring the use of extracorporeal membrane oxygenation
   G. Syndromes associated with progressive hearing loss, such as neurofibromatosis, osteopetrosis, and Usher's syndrome
   H. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome

I. Head trauma
J. Recurrent or persistent otitis media with effusion for at least 3 months

From the Joint Committee on Infant Hearing (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *American Journal of Audiology, 9,* 9-29. As cited in Blackwell & Baker (2002) p. 30.

One may assert that the risk factors identified in this registry can also serve to identify individuals who are at a higher risk for a developmental disability. With improvements in quality and access to medical care in recent years, the mortality of infants in the NICU has dramatically decreased, resulting in more children with hearing loss being seen in audiology clinics for assessment and long-term management (Diefendorf, 2003).

Hearing Impairment in Individuals with Developmental Disability

Hearing loss can arise from a variety of etiologies, "including auricular atresia, ossicular fixation, otitis media, sensorineural deafness, and intracranial tumor" (Green, 2003, pg. 180). Additionally, there are hundreds of syndromes which present with hearing loss as a characteristic feature (Green, 2003). Approximately 2 to 3 cases of congenital hearing loss are reported in every 1,000 live births, making hearing loss the most commonly occurring birth defect in the United States (Vohr et al., 2008). The prevalence of hearing loss is presumably higher for children born with a developmental disability and can present challenges in terms of their ability to develop speech and language skills. In fact, it has been reported in the literature that 2%-4% of children with a developmental disability present with a hearing loss (Diefendorf, 2003). A recent study reported that in a group of 100 children with sensorineural hearing loss, 48 had an

additional disability that was not attributed to the hearing loss (Chilosi et al., 2010). The audiologist has an important role in the identification of individuals with developmental disabilities, as they are often one of the first professionals to evaluate a child presenting with a autism (Rabidoux, 2005) or a speech and language delay (Harvey et al., 2007).

Audiological Assessment of Children with Developmental Disabilities

Audiologists are responsible for identifying pathologies, primarily related to the auditory and vestibular systems, using a combination of subjective and objective assessment techniques. A test battery may include otoscopy, immittance audiometry, behavioral measures of peripheral hearing acuity and speech understanding, electrophysiologic assessments, and a screening of the child's speech and language skills. Performing a comprehensive audiological assessment on a child with a developmental disability presents unique challenges to the audiologist, particularly when the chronological age and developmental age of the individual differs (Diefendorf, 2003). A child presenting with a suspected or diagnosed developmental disability may have physical, cognitive, or visual deficits which prevent them from performing specific tasks that are often used in audiological evaluations. It is recommended that the audiologist spend time during the appointment not only to listen to the concerns of the parents, but also interact with the child and directly observe their behaviors. The audiologist will be more successful in obtaining test results if the child feels comfortable in the environment and if a developmentally-appropriate task is chosen (Diefendorf, 2003; Madell, 2008). Standardized parental questionnaires are can also serve as an effective means of gaining insight into the child's developmental age (Diefendorf, 2003).

Considerations in Assessing Children with Autism

It has been reported in the literature that children with autism exhibit unusual reactions to sensory stimuli (Leekam et al., 2007), with one study reporting a percentage as high as 93% (Billstedt, Gillberg, & Gillberg, 2007). Individuals with autism have been described in the literature as having difficulty integrating sensory information, which can be defined as "impairments in attention and perception and on the integration of perceptual input at a cognitive level" (Leekham et al., 2007, pg. 894). Hence, individuals with autism are purported to perceive stimuli differently than their normally developing peers, consequently causing atypical responses when encountering such events. Prior to audiological assessment, the audiologist should direct some questioning to the parents to determine whether the child has had any negative or atypical reactions to auditory, tactile, and visual stimuli. This could impact the order of tests within the test battery, the information obtained from the assessments, and may indicate the need to make modifications to the test environment in order to make the child more comfortable. This again elucidates the need for the audiologist to be prepared to modify testing techniques based on the child's individual needs, for the purpose of obtaining as much useful diagnostic information as possible. It is often necessary to schedule the child for multiple evaluations to ensure that complete ear-specific and frequency-specific information is obtained. Regardless of the results of the audiological assessment, the audiologist is responsible for making recommendations in relation to the child's speech and language development. This may include a referral to a speech-language pathologist for further assessment in areas related to their discipline (Harris & Dean, 2003).

Considerations in Assessing Children with Developmental Disability, Deafness, and Blindness

Children with a developmental disability who also present with deafness and blindness present a multitude of challenges in audiological assessment. The literature reports that of the approximately 9,500 deaf-blind children (under the age of 22), the majority presented with an additional disability including cognitive, physical, and behavioral disorders (Mascia & Mascia, 2003). Individuals who are deaf-blind with developmental disabilities will have their own way of communicating and it is important for the audiologist to build in ample time to the appointment to become familiar with the patient and their unique communication strategies. Behavioral assessment can be quite challenging, especially since the audiologist cannot visually or orally train the child. Thus, pairing the stimulus with tactile stimulation (i.e. a bone oscillator) may be a way to train the child to associate the sound with a desired response. Once the child is appropriately conditioned, it may be possible to obtain behavioral thresholds. As with any child, objective test measures are of paramount importance in the audiological evaluation (Mascia & Macia, 2003).

Chapter 6: Speech and Language Development and the Role of the Speech-Language Pathologist in the Identification of Individuals with Developmental Disabilities

Overview of Normal Speech and Language Development

Infants show a preference for the human voice shortly after birth (Krentz & Corina, 2008), illustrating the human predisposition to speech and language learning. As with other developmental domains, infants and children advance through a predictable pattern of events as they acquire meaningful speech and language skills. Cooing, which can be described as an open-vowel utterance, emerges between 4 to 6 weeks of age. A progression of bilabial utterances such as, "da", "ba", or "ga" follow at approximately five months of age. This leads to polysyllabic babbling, where the bilabial utterances are sequentially strung together, between 7 to 10 months of age (Blackwell & Baker, 2002; Coplan, 1995). Around 12 months of age a normally developing child will have spoken their first word, and around 24 months of age they begin to put two words together (Coplan, 1995). Table 5 provides a more comprehensive detailing of normal speech and language development from birth to three years of age. These tables can be used by health care professionals to assess a child's speech and language development in the clinic, particularly if a parent raises concerns.

Table 5. Advances toward communication competence*

Age	Comprehension	Oral Expression	Gesture and interaction
Birth-2 mo	Shows preference for mother's voice; may turn/cease movements as she speaks	Cries, burps, hiccups; grunts in relation to body movements	May reproduce some facial gestures of an adult
2-4 mo	Beginning to react positively to changes in intonation of adult	Laughter, cooing, and vocalizations with opening and closing of mouth	Smiling face and excitement to playful adult of object; takes turns vocalizing with adults
4-6 mo	Preference for highly intoned speech	"Wild" sounds & favorite sounds; squeals, yells, raspberries; true vowels appear	
7-10 mo	Responds to word in a usual situation, such as "nono"	Canonical syllables in babbling strings; greater variation in babbling sounds	Eye gaze to show intent; if adult points, child may fixate on hand rather than object
11-13 mo	Understands some common words independent of contest	Vocal imitation; first word	Attends with adult to an object and monitors their attention; follows adult point; infant points to distal objects
13-15 mo	Understands 100-150 words	Babbling and words in what sounds like sentences	Follows adult gaze
16-18 mo	Comprehends 200 words, including action words	Uses at least 50 words; rate of word learning accelerates (18 mo)	Sounds used to call attention to self, object, or people
24-36 mo	Points to the body part when named (24 mo); points to pictures in books (24 mo)	Sentences of 2 to 3 words (24 mo); speech usually understood by people who know child	

*Ages indicate average performance. Look for 2 or 3 delays across or within a category to indicate a need for referral. Ages and method of development relate to acquisition of English in Western cultures and may not be true across all language groups.
Data from Boysson-Bardies, 1999; Carpenter, Nagell, & Tomasello, 1998; Stark, 1980; and Vihman, 1996.

Note: Chart from Blackwell, P. & Baker, B. (2002). *Estimating communication competence of infants and toddlers.*

Introduction to the Speech-Language Pathologist's Role

A speech-language pathologist (SLP) is a professional who specializes in speech, language, communication, and swallowing disorders for persons of all ages. The National Institute on Deafness and Other Communication Disorders (NIDCD) reported that approximately 16% of people in the United States present with some form of communication disorder. Additionally, as many as 9% of children present with a speech sound disorder, and as many as 9 million people have a language disorder (NIDCD, 2010). In a literature review of prevalence estimates of children presenting with a speech and language delay, the authors reported a median result of 5.95% (Law et al., 2000). The prevalence is presumably higher for children with a developmental disability, especially in the presence of an intellectual disability, sensory impairment (i.e. hearing loss), craniofacial anomalies, and other structural anomalies (Schlosser et al., 2007).

Delays in achieving normal speech and language developmental milestones are common motivations for parents to seek the advice of a professional, as "speech and language development is a useful indicator of a child's overall development and cognitive ability and is related to school success" (Nelson et al., 2006, pg. e298). Parents often become concerned when their child fails to make meaningful vocalizations by 12 months of age, or when they recognize that their child's speech and language skills do not match those of their peers (Nelson et al., 2006). A broad understanding of the progression of speech and language development can allow health care professionals to identify children who are at risk for speech and language disorders.

Once a child is referred to an SLP for a speech and language evaluation a detailed history is acquired from the parents and the referring professional. A questionnaire or

written case history form is a time efficient way to obtain key points of information. The SLP details the parents concerns regarding the child's speech and language development, when their concerns first developed, and if there have been any improvements or changes since the problem was first identified. The language spoken in the child's home is of importance, especially when the SLP is choosing an appropriate assessment tool. Furthermore, cultural differences should be taken into account when assessing a child's speech and language development since communication norms differ significantly across cultures.

Chapter 7: Overview of Normal Motor Development in Infants and Children and their Role in the Identification of Individuals with Developmental Disabilities

Modern theories of motor development in infants and children suggest that development of motor skills have an impact on other developmental domains, such as perception and cognition. The emergence of new motor skills are initially immature and occur amid the course of predictable events, just as other domains of normal development. As the infant matures and demonstrates some level of mastery of fundamental skills, their ability to perform more complex motor and cognitive tasks continues to evolve with time and experience (Bushnell & Boudreau, 1993). Motor skill proficiency is "related to health outcomes such as adiposity, self-esteem, cardiorespiratory fitness, and physical activity" (Riethmuller, Jones, & Okely, 2009, pg. e783).

Dominant muscle tone arises in the flexor muscles first, causing full-term infants to exhibit physiologic flexion in all positions until approximately one month after birth. This is in contrast to premature infants, who typically present with an extended trunk and limbs at birth (Aubert, 2008). Within the first three months of life, infants interact with hand-held objects using the palmar grasp reflex. As their coordination improves, they begin to demonstrate the ability to bring objects to midline, and eventually hold it with

both hands (Bushnell & Boudreau, 1993). This illustrates a natural progression of motor control in which infants are able to exercise control medially, where the neck and trunk are more stable, before progressing to the lateral positions (Aubert, 2008). At approximately 4 months of age, visual control allows them to perform more complex motor tasks which are often patterned and circular in nature. These tasks, which are typically displayed using one hand while the other hand is used for postural stabilization may, "include scratching objects, rubbing them, waving and banging them, squeezing and poking them, and passing them from hand to hand" (Bushnell & Boudreau, 1993, pg. 1013). This ability emerges as the infant develops more equal flexor and extensor muscle tone, as well as weight-bearing function (Aubert, 2008). An example of this would be an infant banging an object against a table with one hand, while leaving the other hand firmly planted on the top of the table. In the next phase of motor development, independent postural control enables the infant to experience and manipulate an object with both hands at approximately 10 months of age. Hence, they develop the ability to actively engage in negotiating a toy or object in a less repetitive and more complex way than was previously possible (Bushnell & Bourdreau, 1993). An illustration of this behavior might entail the manipulation of a toy with multiple buttons or knobs using both hands or fingers independently. Between 10 and 15 months of age a normally developing child will typically begin to walk (Aubert, 2008). Table 6 provides a more comprehensive outline of movements that occur between 1 month to 12 months of age. It also provides atypical movements that may occur within the same age group. Table 7 illustrates developmental milestones associated with normal motor development for

children between 13 and 24 months of age. These tables can be used by health care professionals to help identify children with motor delays.

Table 6. Movements Occurring During Infancy

	1 month	2-3 months	4-5 months	6-7 months	8-9 months	10-11 months	12 months
Prone	Elevates head slightly; rotates head to either side	Elbows in line with shoulders for forearm support; lateral weight shifting; rolls to supine	Weight-shifting to free arm and reach with one hand	Elevates trunk with elbow extension; may rock on hands and knees; transitions to sitting; pushes backward	Transitions in and out of sitting to quadruped or prone; pulls to stand without support	Pulls to stand by rolling up over feet; pulls to stand through half kneeling	Stands up through quadruped
Supine	Reciprocal kicking alternates with symmetric kicking	Kicking movements	Alternates feet to mouth and bridging; attempts to roll to side with leg or arm leading	Brings feet to chin or mouth; rolls to prone; attempts to raise self to sit	Raises self to sit	Transitions to sitting and quadruped	Moves rapidly into sitting or quadruped to standing
Sitting	Forward flexion of trunk; head in line with trunk for short intervals	Midline head alignment; minimal head lag during pull-to-sit maneuver; propped sitting may be emerging	Static ring sitting emerging; attempts lateral weight-shift to support body with one arm and grasp a toy with the other	Static sitting while manipulating a toy; weight-shifting with lateral and anterior arm support	Manipulates toy in sitting position; anterior, lateral protective reactions present	Rotates or pivots while sitting to reach; transitions to prone or supine easily	Wide variety of sitting positions includes side-sitting
Upper Extremity	Reaching efforts depend on body position and are linked with visual gaze on object; opens and closes hands	Reaches and grasps with eye-hand coordination; finger play in mouth	Arms extend fully up in supine to reach in midline; palmar grasp on cube; holds toy with two hands	Brings objects to midline; holds bottle with two hands; rakes for small objects	Controlled release; transfers objects; radial digital grasp	Pincer grasp	Rolls a ball; scoops with a spoon; finger feeds
Locomotion		May achieve a 25-30° arc through pivot-prone rotation; rolls from side to back	Pivot-prone rotation; may attempt rocking in quadruped and pushing backward	Moves forward with arms with or without abdomen elevated	Crawls/creeps; pulls to stand with support	Sidesteps or cruises with external support; walks with one hand held	Independent walking with high guard arms and wide support base; lowers self with control from standing May begin to move in and out of a full squat position
Atypical Behaviors	Difficulty flexing legs under body; limited arcs of extremity movement; absence of reciprocal leg movements; no evidence of grasp and release; opistothonis	Inability to right head at end of pull-to-sit maneuver; arching of back	Lateral weight-shifting difficult in prone; unable to extend arms fully and toward midline in supine; kyphotic sitting position; unable to sit erect even with support	Inability to achieve midline head position in supine or sitting; no evidence of movement in prone; inability to tilt pelvis to bring thighs to hands	Commando crawl or bunny-hop; W-sit as the only sitting position	Inability to transition among sitting positions; pulls to standing using arms only; inability to stand on flat feet	Trunk and extremity stiffness, laxity, or instability; poor coordination may prevent hands-knees locomotion and emergence of standing

Note: Table from *Handbook of pediatric physical therapy.* (2002). Long, T., Toscano, K. pg. 3-4.

Table 7. Motor Development From 13 to 24 Months of Age

	13-15 months	15-18 months	18-24 months
Gross motor	Sustained standing without external support; stoops to pick up object and regains standing; stands from floor without support	Carries or pulls an object while walking; creeps down steps; steps on ball positioned for kicking; tries climbing steps using the railing	Stands on one foot momentarily; steps over low barrier
Perceptual motor	Holds two cubes in same hand; builds 2- to 3-cube tower; hurls objects to floor from table or high chair; flings ball with elbow extension	Turns book pages several at a time; scribbles; builds tower with 3 to 4 cubes; takes pegs from board and attempts to replace	Builds 5- to 6-cube tower; places pellet in bottle; separates pop beads; imitates motor activities
Locomotion	Independent walking; climbs into adult chairs; walks backward a few steps; stoops and recovers easily; carries object while walking; creeps up with external support	Base of support almost equal to width of pelvis; running not well coordinated or with arm reciprocation; walks to the side a few steps	Walks up steps with step-to pattern and external one-hand support; running speed and fluidity increasing; tries to jump off bottom step
Atypical behaviors	Moves around environment using bottom scooting, bunny-hop, or rolling	Lack independent, upright walking	Base of support wider or narrower than pelvis; falls often while walking or running

Note: Table from *Handbook of pediatric physical therapy.* (2002). Long, T., Toscano, K. pg. 5.

Hearing Loss and Motor Development

There is evidence in the literature which indicates that children with hearing loss have delays in a range of motor skill tasks, including hand-eye coordination and running. In a study that examined the gross and fine motor skills of prelingually deaf children before and after cochlear implantation, results revealed a "developmental divergence between gross and fine motor skills" (Horn, Pisoni, & Miyamoto, 2006, pg. 1503). Results of the study revealed that the gross motor skills of the younger children with deafness were not as advanced as would be expected in relation to their age when compared with the older children with deafness. Conversely, the younger children with deafness demonstrated more advanced fine motor skills than the older children with deafness when compared to their respective age groups. The author's suggest that this "[indicates] that auditory deprivation, and associated language delay, may impact development of fine motor skills differently than gross motor skills" (Horn, Pisoni, & Miyamoto, 2006, pg. 1503). There is also evidence in the literature which indicates that children with a bilateral moderate to profound sensorineural hearing loss[1] experience a persistent and sometimes progressive delay in gross motor development, which the authors attributed to a hypofunctioning vestibular system (Rine et al., 2000).

[1] A moderate hearing loss is defined as a pure tone average (PTA) threshold of 70-79 dB HL, a severe hearing loss is a PTA of 80-90 dB HL, and a profound hearing loss is a PTA >90 dB HL

Chapter 7: Oral Health Care and an Introduction to the Dentist's Role in Identifying Children with Developmental Disabilities

Oral health care is often overlooked in individuals with developmental disabilities, both due to a lack of qualified service providers and an inadequate understanding of the consequences that poor dental hygiene has on the overall health and quality of life for this population (Seirawan et al., 2008). Oral health has an impact on "nutrition and growth, pulmonary health, speech production, communication, self-image, and social functioning" (Mouradian, 2001, pg. 822). This demonstrates the need for health care providers other than dentists to be invested in the oral health of their patients. The bacterium responsible for caries is commonly passed from mother to child by two years of age. Hence, it is important to educate parents early in the child's life (Mouradian, 2001).

Certain developmental disabilities, particularly those associated with craniofacial anomalies or special dietary needs, make regular dental care an essential element of ongoing treatment. Seirawan et al. (2008) reported that in a study containing 102 subjects , a significant portion were not brushing their teeth every day. These subjects also had, on average, "2 to 3 decayed teeth..., 6 to 7 missing teeth..., and 4 to 5 filled teeth" (pg. 46). This study also found that even when a problem was identified with an

individual's oral health, only a small percentage actually complied with the recommendation to follow up with a dentist (Seirawan et al., 2008).

Individuals with developmental disabilities are more likely to engage in self-injurious behavior including tongue thrusting, hitting the chin or jaw, eating or chewing on objects, and bruxism. These behaviors often lead to more serious oral health problems, such as gum disease. In many cases, the dentist will often need to collaborate with behavioral intervention therapists and other health care providers to address and reduce the occurrence of maladaptive behaviors (Romer & Dougherty, 2008).

Chapter 8: The Role of the Parents, Families, and Caregivers of Children with Disabilities

Stressors Associated with Caregiving for a Child with a Developmental Disability

It is well documented in the literature that parents and family members of children with developmental disabilities have unique stressors related to increased caregiving demands. This can invariably have negative consequences for the child and their families (Plant & Sanders, 2007). The Maternal and Child Health Bureau of the Health Resources and Services Administration sponsored the 2003 National Survey of Children's Health (NSCH), which highlighted some of the personal stressors experienced by families of children with developmental disabilities. Parents of children with developmental disabilities report more difficulty coordinating child care, in part due to the fact that many child care facilities are not willing to care for a child with special needs or behavioral issues. This is compounded by the fact that children with disabilities have more illnesses and absences from school related to their disability, often requiring the parent to take an absence from work to address the needs of their child. This places a significant burden on the parent in terms of employment options. In fact, the survey found that parents of children with autism have more difficulty maintaining employment when compared to parents of children with other developmental problems. Children with disabilities are

more likely to take an absence from a school due to, "suspensions for bad behavior..., victimization by bullies, ridicule, fear of failure, or low self-esteem" (Blanchard, Gurka, & Blackman, 2006, pg. e1209).

Other factors leading to parental stress include the time and complexity of the caregiving task (i.e. feeding, bathing, toileting) and behavioral problems associated with the task. Furthermore, parents of children with more severe disabilities reported a greater degree of stress (Plant & Sanders, 2007). The parents and caregivers may deem some tasks to be unpleasant, thus leading to a higher stress associated with caregiving. This elucidates the need for health care providers to address these types of issues with families and perhaps help the parents brainstorm potential solutions (Blanchard, Gurka, & Blackman, 2006).

The Family-Centered Approach Model to Early Intervention

Federal legislation passed in 1986 (PL 99-457) advocated a family-centered approach to early intervention programs aimed at serving individuals with developmental disabilities (Broggi & Sabatelli, 2010). Parents provide invaluable insight and observations to health care providers with respect to their child's development and evolving needs, making them an integral member of the team. Caregivers are also responsible for taking the child to appointments and reporting critical feedback to health care providers regarding progress and obstacles that are encountered along the way. Through careful evaluation of the parents' input, the team of professionals can direct their assessment tools and intervention strategies in a more constructive direction (Rabidoux, 2005).

A family-centered approach to intervention involves consideration of the patient and their support system (i.e. parents, siblings, and caregivers) when developing an individualized plan that details specific goals, outcomes, and necessary support services which are needed to maximize the individuals potential and quality of life. A key component of this approach is to take into consideration the family's quality of life as well. Professionals are encouraged to empower families to make decisions and to draw on their unique knowledge of the child (Brown et al., 2007). This requires that all team members work towards understanding the dynamic of the family, stressors, lifestyle, and culture (Broggi & Sabatelli, 2010).

Chapter 9: Conclusion

Changes in public policies over the last 50 years reflect significant changes for individuals with developmental disabilities and their families, as well as the communities in which they live. Children with developmental disabilities are often faced with complex medical issues and developmental concerns which are often best addressed through a team approach that puts the child's needs first and foremost. Parents and caregivers of these children undergo a significant amount of stress related to their caretaking duties. Health care professionals should be sensitive to this and be available to help the families problem solve when an issue arises. If implemented properly, a team approach can lead to a more comprehensive and integrated treatment plan for the patient.

There are often a number of allied health care professionals involved in providing services for children with disabilities. Research is now starting to explore the relationship between different domains of child development, demonstrating the importance for every professional working with the pediatric population to be knowledgeable about child development beyond their typical scope of practice. This can ultimately lead to a more timely referral to another professional when risk factors are identified. Audiologists can assist in the identification of children with disabilities by performing developmental surveillance on all pediatric patients. Informal observations of

the child's behavior throughout the audiological evaluation can indicate the need for a developmental screening, especially when the parents and caregivers raise concerns. Although many audiologists do not have the opportunity to work on a multidisciplinary or interdisciplinary team, it is important that each audiologist have a team of professionals to consult with and refer patients to when a concern arises. Ultimately, this leads to better continuity of care for the patient and their family.

References

American Academy of Pediatrics Council on Children with Disabilities. (2006). Identifying infants and young children with developmental disorders in the medical home: An algorithm for developmental surveillance and screening. *Pediatrics, 118* (1), 405-420.

American Association on Intellectual and Developmental Disabilities. (2010). Definition of intellectual disability. Retrieved December 18, 2010 from http://www.aamr.org/content_100.cfm?navID=21.

Association of University Centers on Disability. (2010). UCEDD. Retrieved July 11, 2011 from http://www.aucd.org/template/page.cfm?id=667.

Association of University Centers on Disability. (2010). LEND. Retrieved July 11, 2011 from http://www.aucd.org/template/page.cfm?id=473.

Ashmead, D.H., DeFord, D.L., Whalen, T., & Odom, R.D. (1991). Sound localization and sensitivity to interaural time differences in human infants. *Child Development, 62* (6), 1211-1226.

Aubert, E. (2008). Motor development in the normal child. In Tacklin, J. (4th Ed.). *Pediatric Physical Therapy.* (17-64). Philadelphia: Lippincott Williams & Wilkins.

Bell, A., Corfield, M, Davies, J., & Richardson, N. (2010). Collaborative transdisciplinary intervention in early years - putting theory into practice. *Child: Care, Health, and Development, 36*(1), 142-148.

Blackwell, P. & Baker, B. (2002). Estimating communication competence of infants and toddlers. *J Perdiatric Health Care, 16(*1), 29-35.

Blanchard, L., Gurka, M., Blackman, J. (2006). Emotional, developmental, and behavioral health of American children and their families: a report from the 2003 National Survey of Children's Health. *Pedicatrics, 117*(6), e1202-e1212.

Berger-Sweeney, J. (2011). Cognitive deficits in Rett syndrome: what we know and what we need to know to treat them. *Neurobiology of Learning and Memory,* Article in Press.

Billstedt, E., Gillberg, C., & Gillberg, C. (2007). Autism in adults: symptom patterns and early childhood predictors. Use of the DISCO in a community sample followed from childhood. *Journal of Child Psychology and Psychiatry, 48*(11), 1102-1110.

Broggi, M., Sabatelli, R. (2010). Parental perceptions of the parent-therapist relationship: effects on outcomes of early intervention. *Physical and Occupational Therapy in Pediatrics, 30*(3), 234-247.

Brown, P. (2007). What is meant by intellectual and developmental disabilities. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities* (3-15). Baltimore: Paul H. Brookes Publishing Co.

Brown, P., Galambos, D., Poston, D., Turnbull, A. (2007). Person-centered and family-centered support. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities.* (351-361). Baltimore: Paul H. Brookes Publishing Co.

Brown, I., Radford, J. (2007). Historical overview of intellectual and developmental disabilities. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities* (17-33). Baltimore: Paul H. Brookes Publishing Co.

Bushnell, E. & Boudreau, J.P. (1993). Motor development and the mind: the potential role of motor abilities as a determinant of aspects of perceptual development. *Child Development, 64*(4*),* 1005-1021.

Chilosi, A., Comparini, A., Scusa, M., Berrettini, S., Forli, F., Battini, R., Cipriani, P., Cioni, G. (2010). Neurodevelopmental disorders in children with severe to profound sensorineural hearing loss: a clinical study. *Developmental Medicine & Child Neurology, 52* (9), 856-862.

Choi, B, & Pak, A. (2006). Multidisciplinarity, interdisciplinarity in health research, services, education and policy: 2. Promotors, barriers, and strategies of enhancement. *Clinical & Investigative Medicine, 30, (6),* e224-E232.

Coplan, J. (1995). Normal speech and language development: an overview. *Pediatrics in Review, 16* (3). 91-100.

Diefendorf, A. (2003). Behavioral hearing assessment: considerations for the young child with developmental disabilities. *Seminars in Hearing, 24* (2)*,* 189-200.

Fifield M, Fifield B. 1995. The evolution of university affiliated programs for individuals with developmental disabilities: Changing expectations and practices. Silver Spring, MD: American Association of University Affiliated Programs, ca. 120 pp.

Frankel, E., Gold, S. (2007). Principles and practices of early intervention. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities* (3-15). Baltimore: Paul H. Brookes Publishing Co.

Green, G. (2003). Evaluation of neurologic syndromes with mental retardation and auditory sequelae. *Seminars in Hearing, 24*(3), 179-188.

Guralnick, M. (2011). Why early intervention works: a systems perspective. *Infants & Young Children, 24* (1), 6-28.

Harris, F., Dean, J. (2003). Introduction: assessment of individuals with developmental disabilities. *Seminars in Hearing, 24*(3), 169-170.

Harvey, E., Stanton, S., Garrett, J., Neils-Strunjas, J., Steinberg Warren, N. (2007). A case for genetics education: collaborating with speech-language pathologists and audiologists. *American Journal of Medical Genetics, 143A,* (14), 1554-1559.

Horn, D., Pisoni, D., Miyamoto, R. (2006). Divergence of fine and gross motor skills in prelingually deaf children: implications for cochlear implantation. *The Laryngoscope, 116* (8), 1500-1506.

Joint Committee on Infant Hearing. (2000). Year 2000 position statement: Principles and guidelines for early hearing detection and intervention programs. *American Journal of Audiology, 9,* 9-29.

Krentz, U., Corina, D. (2008). Preference for language in early infancy: the human language bias is not speech specific. *Developmental Science, 11* (1), 1-9.

Larson, S., Lakin, C., Anderson, L., Lee, N., Lee, J., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation, 106 (3),* 231-252.

Law, J., Boyle, J., Harris, F., Harkness, A., Nye, C. (2000). Prevalence and natural history of primary speech and language delay: findings from a systematic review of the literature. *International Journal of Language and Communication Disorders, 35* (2), 165-188.

Leekam, S., Nieto, C., Libby, S., Wing, L., Gould, J. (2007). Describing the sensory abnormalities of children and adults with autism. *Journal of Autism and Developmental Disorders, 37 (5),* 894-910.

Lemieux-Charles, L., & McGuire, W. (2006). What do we know about health care team effectiveness? A review of the literature. *Medical Care Research and Review, 63*(3)*,* 263-300.

Long, T., & Toscano, K. (2002). Growth and Development. In Long, T. & Toscano, K. (2nd Ed.) *Pediatric Physical Therapy* (1-26). Baltimore: Lippincott Williams & Wilkins.

Madell, J. (2008). Evaluation of hearing in children with special needs. In J.R. Madell & C. Flexer, *Pediatric Audiology: Diagnosis, Technology, and Management* (pp. 82-88). New York: Thieme.

Mascia, J., & Mascia, N. (2003). Methods and strategies for audiological assessment of individuals who are deaf-blind with developmental disabilities. *Seminars in Hearing, 24*(2)*,* 211-220.

Mazzocco, M., M., Jeltje, J., Holden, A. (2007). Fragile X syndrome. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities* (173-187). Baltimore: Paul H. Brookes Publishing Co.

Moeschler, J. (2008). Genetic evaluation of intellectual disabilities. *Seminars in Pediatric Neurology. 15*(1), 2-9.

Moeschler, J., Shevell, M., and the Committee on Genetics. (2006). Clinical genetic evaluation of the child with mental retardation or developmental delays. *Pediatrics, 117*(6), 2304-2316.

Mouradian, W. (2001). The face of a child: children's oral health and dental education. *Journal of Dental Education, 65(9),* 821-831.

National Institute on Deafness and Other Communication Disorders. (2010). *Quick statistics for voice, speech, & language.* Retrieved June 18, 2011, from http://www.nidcd.nih.gov/health/statistics/vsl/stats.htm.

Nelson, H., Nydren, P., Walker, M., Panoscha, R. (2006). Screening for speech and language delay in preschool children: systematic evidence review for the US preventive services task force. *Pediatrics, 117*(2), e298-e319.

Nowak, A. (1997). Rationale for the timing of the first oral evaluations. *American Academy of Pediatric Dentistry, 19*(1)*,* 8-11.

Patel, D., Pratt, H., Patel, N. (2008). Team process and team care for children with developmental disabilities. *Pediatr Clin N Am*, *55*(6), 1375-1390.

Percy, M. (2007). Factors that cause or contribute to intellectual and developmental disabilities. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to*

Intellectual and Developmental Disabilities (125-148). Baltimore: Paul H. Brookes Publishing Co.

Percy, M., Lewkis, S., Brown, I. (2007). Introduction to genetics and development. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities* (87-108). Baltimore: Paul H. Brookes Publishing Co.

Petersen, M., Kube, D., & Palmer, F. (2008). Classification of developmental delays. *Seminars in Pediatric Neurology, 5*(1), 2-14.

Pillsbury, H. Grose, J., Hall III, J. (1991). Otitis media with effusion in children: Binaural hearing before and after corrective surgery. *Archives of Otolaryngology -- Head and Neck Surgery, 117*(7), 718-723.

Plant, K.M., Sanders, M.R. (2007). Predictors of care-giver stress in families of preschool-aged children with developmental disabilities. *Journal of Intellectual Disability Research, 51*(2), 109-124.

Rabidoux, P. (2005). Early identification of autism: roles of the speech-language pathologist and audiologist on a transdisciplinary team. *Seminars in Hearing, 26*(5), 210-216.

Rauch, A., Hoyer, J., Guth, S., Zweier, C., Kraus, C., Becker, C., Zenker, M., Hüffmeier, U., Thiel, C., Rüschendorf, F., Nürnberg, P., Reis, A., Trautmann, U. (2006). Diagnostic yield of various genetic approaches in patients with unexplained developmental delay or mental retardation. *American Journal of Medical Genetics, 140A*(19), 2063-2074.

Rice, C., Schendel, D., Cunniff, C., Doernberg, N. (2004). Public health monitoring of developmental disabilities with a focus on the autism spectrum disorders. *Amercian Journal of Medical Genetics, 125C*(1), 22-27.

Rine, R., Cornwall, G., Gan, K., LoCascio, C., O'Hare, T., Robinson, E., Rice, M. (2000). Evidence of progressive delay of motor development in children with sensorineural hearing loss and concurrent vestibular dysfunction. *Perceptual and Motor Skills, 90*(3 pt 2), 1101-1112.

Riethmuller, A., Jones, R., Okely, A. (2009). Efficacy of interventions to improve motor development in young children: a systematic review. *Pediatrics, 124*(4), e782-e792.

Romer, M., & Dougherty, N. (2008). Oral self-injurious behaviors in patients with developmental disabilities. *Dental Clinics of North America. 53*(2), 339-350.

Rosenberg, S., Zhang, D., & Robinson, C. (2008). Prevalence of developmental delays and participation in early interventions services for young children. *Pediatrics, 121*(6)*,* e1503-e1509.

Schlosser, R., Sigafoos, J., Rothschild, N., Burke, M., Palace, L. Speech and language disorders. In Brown, I. & Percy, M. (1st Ed.). *A Comprehensive Guide to Intellectual and Developmental Disabilities.* (383-401). Baltimore: Paul H. Brookes Publishing Co.

Seirawan, H., Schneiderman, J., Greene, V., Mulligan, R. (2008). Interdisciplinary approach to oral health for persons with developmental disabilities. *Spec Care Dentist. 28*(2), 43-52.

Shaffer, L. (2005). American College of Medical Genetics guideline on the cytogenetic evaluation of the individual with developmental delay or mental retardation. *Genetics in Medicine, 7*(9), 650-654.

Shapiro, B.K., Menon, D.U., & Accardo, P.J. (2008). Clinical overview of the autism spectrum. In B.K. Shapiro & P.J. Accardo, *Autism Frontiers* (pp. 1-20). Baltimore: Paul H. Brookes Publishing Co.

Shevell, M., Ashwal, S., Donley, D., Flint, J., Gingold, M., Hirtz, D., Majnemer, A., Noetzel, M., Sheth, R.D. (2003). Practice parameter: Evaluation of the child with global developmental delay. *Neurology, 60*(1 of 2), 367-379.

Shevell, M. (2006). Office evaluation of the child with developmental delay. *Seminars in Pediatric Neurology, 13*(4), 256-261.

Shevell, M. (2008). Global developmental delay and mental retardation or intellectual disability: Conceptualization, evaluation, and etiology. *Pediatr Clin N Am, 55*(5), 1071-1084.

Shevell, M. (2010). Present conceptualization of early childhood neurodevelopmental disabilities. *Journal of Child Neurology, 25(1)*, 120-126.

Sininger, Y.S. (2007). The use of auditory brainstem response in screening for hearing loss and audiometric threshold prediction. In R.F. Burkard, M. Don, & J.J. Eggermont, *Auditory Evoked Potentials* (pp. 255-274). Baltimore, MD: Lippincott Williams & Wilkins.

Sininger, Y. S., Doyle, K. J., & Moore, J. K. (1999). The case for early identification of hearing loss in children. *Pediatric Clinics of North America , 46*(1), 1-8.

Vohr, B., Jodoin-Krauzyk, J., Tucker, R., Johnson, M.J., Topol, D., & Ahlgren, M. (2008). Early language outcomes of early-identified infants with permanent hearing loss at 12 to 16 months of age. *Pediatrics, 122*(3)*,* 535-544.

Yoshinaga-Itano, C., Sedey, A.L., Coulter, D.K., & Mehl, A.L. (1998). Language of early- and later-identified children with hearing loss. *Pediatrcs, 102*(5), 1161-1171.